



## Residential Study Advisory Council

Seattle Sea-Tac Hilton  
October 20, 2005

**NOTE: refer to the Council's agenda attached to these meeting notes.**

**Council Members Attending:** Dale Colin, Greg Devereux, Lori Flood, Marcy Johnsen, Kathy Leitch, John Mahaney, Lance Morehouse, Karen Ritter, Senator Dale Brandland, Senator Adam Kline, Representative Brendan Williams, Representative Jan Shabro, Kari Burrell

**Staff Members Attending:** Gaye Jensen, Jonnel Anderson, Sharon Swanson, Donna Patrick, Ed Holen, Chelsea Buchanan, Amy Hanson, Tom Lineham, Don Clintsman, and outside Facilitator Marge Mohoric

**Guest Legislator:** Representative Ruth Kagi

### **Kari Burrell, representing Governor Gregoire, summarized the Proviso creating the Council**

- ❑ The Governor wanted to step back and gain input and data on services needed. We are at a fork in the road--the Legislature did not fund facility improvements and is interested in a long-term plan for services. As we think about the system we want, we need to think about reorganizing or reallocating the existing resources we have to meet the needs.
- ❑ The Proviso provided \$182,000 in the Office of Financial Management's budget for study of DD residential services.
- ❑ Perhaps we develop Plan A and Plan B with one being needs if we had the budget, and Plan B what we could do with limited funds.
- ❑ The Governor proposes the project be sequenced in phases:
  1. **Phase I** – data collection and assessment phase
  2. **Phase II** – visioning--where do we want to go; what do we want the system to look like in the future?
  3. **Phase III** – what do we need to do to get to our preferred future (e.g. sequencing, costs, etc.)?
- ❑ Work Plan – We are suggesting an amendment be made to the Proviso extending the project out a year with the Council working hard in the next 3 months to complete Phase I and develop an interim report to the Legislature this January. We could then continue Phases II and III to continue visioning and implementing in 06-07.

### **Council's Discussion (members were asked to complete the sentence "I will be happy 1-1-06 if the following happens")**

- ❑ This system does support families, not just when they are children but adults. There is an emerging issue of aging care givers—how to continue that service for/with them; as more people live longer. Aging caregivers cannot care for them any more. We need to consider the aging caregivers now.
- ❑ The timeline Kari laid out is realistic.
- ❑ The timeline needs to be extended. In the meantime, until we can implement the new plan, I'm concerned about the people who are waiting for services and how we will address this when we implement. We need to develop strategies for that as well. Families feel they are now on hold.
- ❑ I am also concerned about the fact there is no one from the RHC on this committee and concerned that this is a very ambitious task we are facing.
- ❑ I'm not so concerned about the data collection. Kathy Leitch and others have good data and we will have information we need. Although we can't extend the 4-year plan, we need to give the Legislature direction January 1 of 2006.
- ❑ It is ambitious to have a plan by 1-1-06. Having monitored previous task forces they can go on for a long time—we need to stay focused and get it done in the next year.
- ❑ I am pleased to see the proposal to extend the timeline. Having worked in the state system I've seen many planning groups who met for a long time and much of that work went unheeded. I'm hopeful that the study we do is implemented. Regarding someone in an RHC being part of this group, some of them are profoundly needy and cannot speak for themselves.
- ❑ The timeline is not just a matter of the Legislature asking this Council to make recommendations—but there is civil discord going on between community representatives and RHC representatives. This extension for 1 year should be possible. We are not in a rush here and should consider the details and go slowly.
- ❑ I thought it was a misprint that we need to have something complete by January 1 2006. I don't know the volume of data that will be necessary for us to be making decisions. We need good data to make good decisions and we need to take more time for that. Ideally I would like to see a preliminary idea of what our Vision looks like before 1-1-06. We can then begin to shape policy decisions and get feedback. That doesn't mean it can be firmly in place, but the more information, the earlier, the better.
- ❑ There is tension between the desire to be thorough and make sure everyone's voice is heard and to move to make decisions. I hope we can be thorough about what we need to know so staff can keep all of this moving toward the goal.
- ❑ 1-1-06 is too ambitious but I hope we won't go too far the other way. We've had processes like this too long—we need to limit this so we accomplish things. By 1-1-06 if we can make some good judgments about how to move forward, then we can talk about best practices and move forward. We need to look at aging family situations. We need to help them plan for the future. The Governor has heard from

people that the downsizing of Fircrest is appropriate, and from those that think it is inappropriate.

- ❑ We need to figure out what we're going to do and not take too long. We need to know how many meetings it will take. It is important that the group take time to listen to what self-advocates out there want in terms of residential services.

### **Don Clintsman Presentation: "Introduction to the Division of Developmental Disabilities and Residential Services" (refer to attached PowerPoint Presentation)**

- ❑ Federal definition of developmental disability/Washington State eligibility criteria
- ❑ DDD Residential Services: RHCs and community-based care settings
- ❑ Residential statistics by regions

### **Highlights of Council Discussion:**

- ❑ Request for RHC budget figures, including budget figures for mental health services for people with dual diagnosis
- ❑ Request for % of adults who live at home with their families. How many receive Medicaid Personal Care services? How many clients over 40 years of age live with their parents? May want to consider these folks as part of this study.
- ❑ Request for more information on Companion Homes.
- ❑ Request for residential data organized by county
- ❑ Request for DD foster home data
- ❑ Request for explanation of waivers
- ❑ Interest in knowing if there is data on private pay clients

Reply: there is no database to track clients who pay privately for their own services

- ❑ Request for profile of nursing home clients in the RHCs as compared to community nursing homes
- ❑ Request for information about waiting list demographics (age, likelihood of need for more structured setting, rural v. urban)

Reply: The Department of Social and Health Services is working on developing an automated assessment process. With a "mini-assessment" process currently taking place. May be able to look at each quarter's data.

- ❑ Concern expressed for waiting list of 9000 families (unofficial number) waiting for services.

- ❑ Question about whether people with financial means should pay for their own services.

### **Amy Hanson Presentation: “Historical Context, Studies, Legislation, and Budget Actions” (refer to attached PowerPoint Presentation)**

- ❑ History and timeline of major events affecting individuals with developmental disabilities
- ❑ Summary of key studies and reports
- ❑ Summary of recent budget and legislative actions

### **Highlights of Council Discussion:**

- ❑ Question: Is there a forecast on the RHC census? What is the admissions policy?
- ❑ Question: So many studies have been done—what can this Council do that’s different?
- ❑ Comment: Trend to downsize is not unique to Washington. We probably have more people in institutions than the national average. Part of the issue is how do you decide when you close an institution in light of all of these studies and data?
- ❑ Comment: admissions are limited even when linked to choice because of lack of funds in the community.
- ❑ Comment: Many families don’t want children to grow up in large institutions, but to live with brother/sisters and neighbors. Choices shouldn’t be made out of desperation.
- ❑ Comment: There are positive things about all of the settings; each study we reach a stalemate and our current hope is that perhaps the individuals who assemble themselves here can figure out strategies that will work for everyone.
- ❑ Comment: The limited resource issue has been skirted in the past. Where do we go today-- given the resources we have, are we allocating them in the best and highest use of those dollars?
- ❑ Comment: It’s not just about money. Land could be better utilized without sacrificing services. We have one of the Top Ten nursing homes in the nation at Fircrest. Could that be funded by ADSA/LTC?

- ❑ Comment: This is a very political issue and it's also a Union issue. What is refreshing about this group is there are 4 Legislators on this group and I'm expecting a different result.
- ❑ Comment: We all need to have first and foremost in our minds—what is best for individuals with DD? We have waiting lists and we need to think about the wise use of dollars.
- ❑ Comment: If we can set aside our personal bias, and we can find solutions that will work for all. We all need to make sacrifices from tightly held positions. Its not an either or. We can try to integrate people and money.
- ❑ Comment: Hope some day we represent every worker—if it's a union issue it's a positive one fighting for the service for people who need them.
- ❑ Interest expressed in arranging tours of residential programs for members of the Council

## Written Public Comment:

### Commenter 1:

1. A. In comprehensive detail, what are the client needs, available services and associated costs? Include full range of needs, categories of services needed and their geographic availability. Include cost of all services, especially including those not previously kept, figured or reported. To the extent that any of this information is missing, recommendations, which are made, by the Council or decisions by lawmakers will be ill founded. Providing this detail can be what sets this council's work apart from all of the others, which have preceded it. B. Assess and recommend how the services can be provided most appropriately to those who need them, taking into account all of the associated costs.
2. While to the uninitiated, they appeared and sounded reasonable, those of us who are familiar with the studies summarized in this afternoon's presentation are aware that they were, at once, biased and flawed. There is a long history of such in-house skewing of information. How will the council assure that its work is based on accurate and complete information and can be regarded by legislators and the public with credibility? Will the Council consider hiring an outside contractor, such as the Policy Consensus Center, to obtain/assess the data? (Especially with regard to much of the missing community data, collection/aggregation procedures have not previously even been in place.)
3. If I heard correctly, we were told that DDD clients living in their families' homes are not counted in the statistics on how many are served. Why is that, and how many are there?
4. What are the categories of needs represented by the unserved part of DDD's clientele and how many people are represented by each category?

5. Both of today's power-point presentations contained assumptions, which focused the group in certain ways and left erroneous impressions, which then served as the basis for further discussion. Can a process be built in which allows for more timely input from spectators, but is not unproductively disruptive to the council's deliberations in case something similar is noted again? For instance, could a written comment or question be passed to the facilitator while the discussion is ongoing?
6. One of the legislators has referred to this issue as "Northern Ireland." What measures might this council take in order to be able to address the mandate of developing meaningful recommendations without recreating the "Northern Ireland" syndrome during it's deliberations?

**Commenter 2:**

1. What can be done about the DDD philosophical bias against RHC's? Shouldn't RHC's be independent of DDD and Aging and Adult Services? It's a problem for the fox to guard the henhouse
2. How can DDD data and information achieve neutrality? DDD data and numbers are historically biased against RHC's.
3. How can you get an RHC res. Guardian on the Council, as the enabling law requires?

**Commenter 3:**

1. Policy of the ARC of the US is that large congregate care facilities are neither necessary nor appropriate for people with DD. Virtually all the professional organizations in DD field that I am aware of say that best practices are toward community-based services.
  - a. Matter of civil rights
  - b. Basic rights of people—where they live, w/whom they live, what they do with their lives
2. Families need support—we work with a lot of unserved families some desperate for services in their home and community—too long denied services
3. With more support people with DD can thrive in the community. Families we work with do not want respite in the institutions; they want respite in their homes and communities.

**Commenter 4:**

Not a question, just a statement: Page 17, item 5, because of downsizing at Fircrest, we can no longer provide respite care. Our professional services to community clients have been discontinued by the Department (DDD).

**Commenter 5:**

Is there a JLARC person on staff (e.g. John Woolley or Deborah Frazier)? Because the 2003 JLARC Perf. Audit of DDD \* (\*different from the Capital study) has valuable cost information in it and should be distributed to Council.

**Commenter 6:**

1. Costs—RHC costs are well defined due to matching funds, yet community funds/costs are not always available. How can costs be accurately compared?
2. Tour the facilities (RHC's) and Group Homes Community (ICF/MR)

**Commenter 7:**

1. What is the true assessment of the unmet and partially met needs of persons who are eligible for ICFMR level of care?
2. What is the true cost of providing the full array of services?
3. What is the most appropriate setting for the most profoundly mentally retarded of the developmental disabilities population?

**Commenter 8:**

1. Could we close the RHC's and open more SOLA's as a way to continue high quality care for people? Wouldn't we be able to support more people and maintain state jobs?
2. Is there really a difference in death rates between community and RHC's?
3. How do quality standards vary between the community and RHC's?
4. What are the results of quality reviews in the RHC's and the community?

**Commenter 9:**

1. Look at the State of the States data from Braddock (national data on shift to comm. services).
2. On whose behalf or for whose benefit are these decisions being made—people with DD or state employees who want to keep their jobs?

**Commenter 10:**

1. What are the average costs of each type of residential service AND what are the services levels and contractual obligations of each of them?
2. What are the preferences of most people wanting residential services?

**Commenter 11:**

1. Can't we have both?
2. Why can't we use the specialties at the facilities to serve the community?
3. What is the true comparison of RHC and community if given the same service-- medical, PT-OT, vocational and leisure?
4. Why Fircrest, why not start with smaller facility?
5. How much and for how long will closing Fircrest (or any facility) save and give to those in the community?
6. If facilities close, what kind of community residence system do we use—the variety we have now, one of what we have now, or a whole different system?

**Commenter 12:**

1. How and when should institutions be closed? Do we need a closure model?
2. How can our state rebalance its resources to meet the unaddressed need for community-based services?

3. How can we ensure that the voice and values of people with developmental disabilities come first as we develop a preferred system of services?

**Commenter 13:**

1. Where can people with DD live enriched and integrated lives as a member of a community?
2. Where is the best place for people to have the highest quality life and home in which they have power and choice?
3. How can we ensure a stable and secure community services system that is able to meet the growing need?

**Commenter 14:**

1. True choice for people=RHC, Group Home, ITS, Independent Living
2. Cost vs. service=more bang for the buck
3. Effect that lobby groups have and results of this meeting 1199, ARC, WFSE, King County, parent to parent, etc.

**Commenter 15:**

1. With about 1,000 people currently served in our RHC's at an average annual cost of about \$180,000 per year per person, along with about 11,000 people who have no paid service, how can the resources of the existing system be redistributed?
2. In 2005, what are the critical questions that need to be answered in order for a recommendation to be made?
3. Ten other states have closed all their state institutions for people with developmental disabilities, what would it take for our state to follow suit?

## **Future Meeting Dates/Location**

### **NOVEMBER COUNCIL MEETING: Friday November 18, Sea-Tac Hilton**

#### **STAFF SUGGESTED AGENDA ITEMS**

1. Overview of DDD's Assessment/Eligibility Determination Process
2. Medicaid 101
  - a. State Plan
  - b. Waivers
3. Institutional-based Residential Services
  - a. Client Profile
  - b. Geographic Distribution
  - c. Costs/Funding
4. Community-Based Residential Services
  - a. Client Profile
  - b. Geographic Distribution
  - c. Costs/Funding

### **DECEMBER COUNCIL MEETING: Thursday December 15, Sea-Tac Hilton**



#### STAFF SUGGESTED AGENDA ITEMS

1. What do other states do?
  - a. Comparative Data
2. Emerging Issues
  - a. e.g. Aging care givers issue